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ABSTRACT

In 1987 Congress made available a one-time, 1-year emergency appropriation to pay for Food and Drug Administration (FDA)-approved life-sustaining drugs for people with Acquired Immune Deficiency Syndrome (AIDS). New Jersey received $1.5 million from this program for antiviral drugs for low-income people with AIDS and AIDS Related Complex lacking other public assistance. The Emergency Retrovir Reimbursement Program (ERRP) provided 175 person-years of Aziodothymidine (AZT). Other sources of funds for AZT in New Jersey included General Assistance, Medicaid. and a Pharmaceutical Assistance Program for the Aged and Disabled (PAAD). The ERRP was arranged to maximize convenience for applicants. With federal approval, income levels for ERRP were substantially higher than for other assistance programs. The program was publicized widely; application processing took 2 weeks. The existing mechanism for reviewing applications for Medicaid and PAAD was used for ERRP. The centralized processing allowed non-qualifying clients to get on other appropriate programs. Approximately 15 percent of those applying for ERRP in its first year were approved for Medicaid or PAAD coverage of AZT. The ERRP also covered co-payment for AZT required of clients with third party coverage who met income criteria. The program made direct payments for AZT to pharmacies. Characteristics of enrollees in the various AZT entitlement programs in New Jersey are described. (Author/ABL)

NEW JERSEY'S EMERGENCY RETROVIR REIMBURSEMENT PROGRAM (ERRP)*

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ABSTRACT

New Jersey received $1.5 million from Congress for antiviral drugs for low-income people with AIDS and ARC lacking other public assistance, enough to provide for about 175 person-years of AZT (Retrovir). Other sources of funds for AZT in New Jersey include General Assistance, Medicaid, and a Pharmaceutical Assistance Program for the Aged and Disabled (PAAD). The ERRP has been arranged to maximize convenience for applicants. With federal approval, income limits for ERRP were set substantially higher than for other assistance programs. The program has been publicized widely; application processing takes two weeks. The existing mechanism to review applications for Medicaid and PAAD is used for ERRP. This centralized processing allows non-qualifying clients to get on other appropriate programs; about 15% of those applying for ERRP in its first year were approved for Medicaid or PAAD coverage of AZT. ERRP also covers co-payment for AZT required of clients with third party coverage who meet income criteria. The program makes direct payments for AZT to pharmacies. Characteristics of enrollees in the various AZT entitlement programs in New Jersey are described.

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NEW JERSEY'S EMERGENCY RETROVIR REIMBURSEMENT PROGRAM (ERRP)

Background

In 1987 Congress passed a Federal Supplemental Appropriations Act, PL 100-71. Section 319 of this law made available to the 50 states, the District of Columbia, and eight U.S. territories a one-time, one year emergency appropriation of $30 million. This appropriation's purpose was to pay for Food and Drug Administration (FDA)-approved life-sustaining drugs for people with AIDS (PWA). Only one such drug has been approved by the FDA. It is known by a scientific name, Azidothymidine or AZT; a generic name, Zidovudine; and a trade name registered to the Burroughs Wellcome Co., Retrovir.

The decision by Congress to make a special appropriation for this life-sustaining drug was related to the costliness of AZT. A full dosage, two capsules taken six times a day, cost approximately $10,000 a year at a retail pharmacy at the time the law was passed; a subsequent price reduction, on December 12, 1987, brought the price down to a still expensive $8,000 a year. Some people with AIDS suffer intolerable side effects from taking AZT, such as anemia, making it inappropriate for them; others are prescribed less than the full dosage. Under the terms of PL 100-71, each state, district, or territory was entitled to a minimum of $30,000 to provide AZT for PWA. Above this amount, the distribution of funds was based on the proportion of living AIDS cases that each state, etc., reported to the Centers for Disease Control (CDC) as of July 6, 1987, out of the total of 16,441 living cases reported on that date. Nine states and five territories qualified for only the minimum amount, and two territories declined the funds. In the remaining political entities--Puerto Rico, the District of Columbia, and the 41 states with 17 or more AIDS cases reported on the index date--the appropriation amounted to $1,824.70 per living person with AIDS. New

Jersey's share of the appropriation totalled $1,532,748; its 840 living PWA ranked it fifth at the time.

This amount was equivalent to coverage for a full dosage of AZT for a year for about 150 New Jersey residents, at the early 1987 price, and about 190 people after the price reduction. The federal law left it to each state to make its own determination of eligibility for AZT under this emergency reimbursement program; sliding income scales and copayments were allowed. In general, the funds were intended for PWA who did not have third party health coverage through Medicaid or private insurers. In addition, the funds were to provide AZT for those with Medicaid in states where it does not cover prescriptions in general or AZT in particular. (See Buchanan, 1988, for a survey of Medicaid coverage of AZT.) This paper describes how New Jersey has implemented its Emergency Retrovir Reimbursement Program (ERRP) and describes demographic characteristics of those obtaining AZT through this and other entitlement programs.

Combining ERRP and Other AZT Entitlements

Prior to the Emergency Retrovir program, New Jersey was one of the majority of states that provide AZT through Medicaid; there were also other sources of funding for AZT, as we will describe shortly. The availability of AZT in New Jersey is one small part of the state's pioneering efforts in providing medical care for PWA. These efforts also include an uncompensated care program in all of the state's hospitals and two programs promoting community-based care. An Uncompensated Care Trust Fund in New Jersey assures that no person is denied hospital care (including prescription drugs such as AZT prescribed to inpatients) because of an inability to pay for it. Among PWA, however, a lack of nonacute care facilities early in the epidemic was resulting in some very long and costly hospital stays.

Consequently, in 1986 the state sought and received funds from the Robert Wood Johnson Foundation's AIDS Prevention and Service Program to promote community-based care. This program has located case managers in several major hospitals who help to develop a continuum of care for PWA in their geographic area and facilitate the timely discharge of hospital patients to community-based sources of care. In addition, the state was awarded the first Medicaid Home- and Community-Based Services Waiver early in 1987. County-based case managers in this program are responsible for finding less costly alternatives to institutional care for PWA. In addition to case management, the Medicaid Waiver offers private duty nursing, medical day care, personal care assistants, drug abuse treatment, and foster care; a hospice program is in development.

With regard to coverage for drugs, New Jersey has for several years had a program for Pharmaceutical Assistance for the Aged and Disabled (PAAD) that is funded from casino revenues. This program has higher income eligibility ceilings than Medicaid, and because AIDS is regarded as a disability, PWA who meet PAAD eligibility criteria can receive AZT through this program. One administrative mechanism is used in New Jersey to determine eligibility for both Medicaid and PAAD. The Department of Health decided to use this same mechanism to determine eligibility for the Emergency Retrovir Reimbursement Program. Because Medicaid and PAAD are administered through the Department of Human Services, this required that the Department of Health enter into a memorandum of agreement with this other Department to process AZT applications under the ERRP. It entered into a similar agreement with the Prudential Insurance Company to process claims for the ERRP, just as it does for Medicaid and PAAD.

Combining the ERRP eligibility determination with that in existence for Medicaid and PAAD made it possible for those doing the processing to route applicants to the appropriate program for reimbursement for AZT. This contrasts with the usual experience of those seeking public assistance, who typically have to make an

independent application to each entitlement program. In this typical scenario, applicants who are denied coverage then face another waiting period without benefits. Combining the eligibility determinations has made it possible for the New Jersey mechanism to process applications in two to three weeks. In a move further to facilitate the timely dispensing of AZT to those in need, New Jersey's ERRP adopted a 'pay and chase' philosophy. Under it, the program makes immediate payment for AZT to participating pharmacies on behalf of PWA, and it then seeks the payer deemed to be appropriate for the person under consideration.

One stipulation of the federal legislation making the funds available is that none of the allotment should go for administrative purposes. Therefore the Department of Health transferred $20,000 in state funds to the Department of Human Services to process applications in the first year of the program, with another $20,000 available for systems development, maintenance, and claims processing.

To be eligible for the ERRP, applicants must meet the following criteria:

- New Jersey residency;
- AZT reimbursement that is not fully covered by other third party payers, including
    - General Assistance (welfare),
    - Medicaid,
    - PAAD, or
    - commercial insurers;
- income $\leq$ $25,000 for single individuals and $30,000 for married people;
- a letter accompanying the application from a physician attesting to a medical necessity for AZT (Note: it is thus up to a physician to decide whether an HIV+ person who has not yet developed AIDS or ARC can be enrolled in the program.); and

- a letter of agreement with a Medicaid and PAAD participating pharmacy to dispense AZT.

Publicity for the program included press releases and an advertising campaign. Among the groups specifically notified were all 18,000 physicians in the state; all acute care hospital administrators and social workers; primary treatment clinics; drug, alcohol, and family planning clinics; Medicaid offices and other third party payers; the Robert Wood Johnson Foundation program case managers and Medicaid case managers; and the state-run New Jersey AIDS Hotline. The Hotline was a key link with the application process, since publicity for the program asked that applicants call the Hotline at (609) 588-7039 for application forms. Two thousand such forms were prepared, and a special post office box was set aside to receive them at the PAAD office. We have noted that the processing of applications is done within two to three weeks. In addition, letters of approval are issued--when appropriate--to the applicant, the sponsoring physician, and the participating pharmacy. Reimbursement forms are sent to the pharmacy along with the letter of approval, and these are processed within two to three weeks after they are sent to the PAAD office. Confidentiality measures prohibit public access to identifying information about AZT applicants, but a tracking system keeps account of client participation and expenditures on a monthly basis.

The federal program allocating money to the states was scheduled to expire on September 30, 1988, with all unexpended funds reverting to the federal government for redistribution to states demonstrating a need for additional resources. However, the federal government also allowed for the transfer of unexpended funds to a financial intermediary within each state. In New Jersey, that role has been taken on by the New Jersey Pharmaceutical Association.

Table 1 summarizes the various public entitlement programs through which PWA in New Jersey can obtain AZT, and the financial criteria that apply to each program. Note that those with private insurance who must make a co-payment for drugs (as major

medical plans often require in the amount of 20%) can obtain ERRP funding for the co-payment if their incomes fall under the eligibility ceiling.

TABLE 1. PUBLIC ENTITLEMENT PROGRAMS FOR AZT IN NEW JERSEY

CRITERIA	PROGRAM
Income < $2388, no assets	General Assistance (75% state, 25% local)
Disabled (incl. SSD), AFDC	Medicaid
Supplemental Security Income (SSI)	Medicaid (medically disabled)
Income < $3996 after medical bills, assets < $3600	Medicaid (medically needy)
Income < $13,650 (single), $16,750 (married)	Pharmaceutical Assistance for the Aged and Disabled (PAAD)
Income < $25,000 (single), $30,000 (married)	Emergency Retrovir Reimbursement Program (ERRP)

Who Has Received AZT Through New Jersey's Entitlement Programs

Thus far we have discussed how people can qualify for the ERRP. In the remainder of the paper, we will describe how the program has worked and whom it is reaching. Table 2 shows that through September 1988, over 1600 claims for AZT had been processed and nearly $370,000 worth had been dispensed through the ERRP. The program has been growing rapidly; out of the one year total, nearly 20% of the funds--over $71,000--were paid out for AZT in the last month.

As Table 2 shows, 287 of the 356 ERRP applicants had received (or had pending) approval for AZT during the program's first year. Another 40 applicants were found to qualify for AZT through either Medicaid or PAAD, and 22 more were already on Medicaid or PAAD at the time they applied to ERRP. In all, then, the application

procedure for ERRP identified 62 individuals (or about 17% of those submitting applications) who were eligible to receive AZT through some other entitlement program. Fewer than 2% of applicants did not qualify for AZT through some such program.

TABLE 2. THE ERRP IN ITS FIRST YEAR (10/87 THROUGH 9/88)

Claims Processed 1631			Paid Out $369,580.13
Total Applicants		356	
Potential Recipients		287	
Accepted	270		
Pending	17		
Qualified for Other Programs		40	
Medicaid	35		
PAAD	5		
Denied		26	
Already on Medicaid	9		
Already on PAAD	13		
Other Insurance	3		
Out of State	1		
No Longer Required AZT		1	
Deceased Before Approval		2	

Data on the compliance of AZT recipients with prescribed regimens proved to be difficult to analyze. However, anecdotal evidence from case managers suggests that compliance is generally quite good.

Our final table (Table 3) gives demographic profiles of the populations receiving AZT through the various entitlement programs available in New Jersey. This analysis is based on a linkage of program records with the confidential files in the New Jersey AIDS Registry. By law, reporting of all AIDS cases to the Registry has been required since October 1986; Registry personnel believe that 90% or more of the state's AIDS cases are in fact reported. However, many cases of ARC are not, and HIV seropositivity is not reportable. Hence our demographic profiles of AZT recipients

TABLE 3. DEMOGRAPHIC CHARACTERISTICS OF THOSE RECEIVING AZT THROUGH ENTITLEMENT PROGRAMS IN NEW JERSEY, 10/87-9/88

	PROGRAM	W'fare	M'aid	PAAD	ERRP	Total	Registry Adults
	Total N	32	504	59	217	812	
	Linked w/ Reg (1)	12	391 (2)	27	114 (3)	544	5153 (4)
CHARACTERISTIC							
GENDER	Male	67%	75%	93%	75%	76%	80%
	Female	33%	25%	7%	25%	24%	20%
RACE	Black	92%	41%	26%	35%	40%	52%
	White	8%	41%	48%	49%	42%	35%
	Hispanic		16%	22%	12%	15%	13%
	Oth/Unk		2%	4%	4%	2%	0%
RISK FACTOR							
	Gay/Bi Male	8%	20%	41%	26%	22%	28%
	IVDU	75%	58%	26%	41%	53%	54%
	Gay/Bi IVDU		5%	7%	4%	4%	5%
	Hetero Trans	8%	9%	4%	11%	9%	8%
	Other (5)		2%	4%	6%	3%	3%
	Undetermined	8%	6%	19%	11%	8%	2%
HIV MANIFESTATION							
	AIDS	75%	89%	93%	71%	85%	66%
	ARC	17%	7%	4%	22%	10%	14%
	Other	8%	4%	4%	7%	4%	21%
VITAL STATUS							
	Alive	100%	67%	37%	88%	71%	38% (est.)
	Dead		28%	52%	7%	24%	54% (est.)
	Unknown		5%	11%	5%	5%	10% (est.)
AGE	Average	38	35	41	34	35	35

NOTES

(1) No. linked with NJ AIDS Registry entries for demographic information
(2) Includes 19 people also on PAAD between 10/87 and 9/88
(3) Includes 2 people also on ERRP between 10/87 and 9/88
(4) Total adult cases reported from 1981 through 10/31/88
(5) Hemophilia, transfusion, and parent at risk

describe chiefly those with AIDS. An inspection of the rows in Table 3 labeled HIV MANIFESTATION will confirm this assertion.

Different proportions of those in the various AZT entitlement programs are included in our Registry-linked sample. This may be seen by comparing figures in the top two rows of Table 3. Over 3/4 of those receiving AZT through Medicaid are included in the sample. However, the sample includes only about 1/3 of the small number of General Assistance (Welfare) AZT recipients and about 1/2 of those receiving AZT through PAAD or ERRP. We do not know whether the remainder of AZT recipients through these programs are unreported AIDS cases, ARC cases, or people who are HIV positive but have developed no disease symptoms.

The rightmost column of Table 3 shows the demographic composition of the adult population in the New Jersey AIDS Registry as of the end of October 1988. Comparisons between this last column and the others are instructive. In general, females are somewhat overrepresented among those receiving AZT relative to their proportion in the Registry. This is true of those getting AZT through ERRP and all other entitlement programs except for PAAD. Blacks, on the other hand, are significantly underrepresented among those receiving AZT through all programs except General Assistance, which serves the poorest sector of the population. This suggests a need for the state to provide more information about the availability of AZT to New Jersey's black population.

Intravenous drug users (IVDU) appear about as frequently in the population of AZT recipients overall as in the Registry. Note that they are concentrated particularly in the programs with the lowest income ceilings, as shown by the high percentages of IVDU among recipients of General Assistance and Medicaid. The proportion of recipients still alive at the time of the study substantially exceeded that in the Registry (which goes back to 1981), except for those in PAAD, whose vital status distribution parallels that in the Registry as a whole. Note that PAAD

recipients of AZT are older on average than the others; in other research (Rothenberg et al., 1987; French and Conviser, 1988), people with AIDS aged 40 or above have been shown to have significantly lower than average life expectancies. With this exception, AZT appears to be succeeding in sustaining the lives of those who receive it through New Jersey's entitlement programs.

For some of these people, however, the continued availability of AZT may be in jeopardy. Given the rate of expenditure of ERRP funds toward the end of the year covered by this study, these funds appear to be enough to sustain the program in New Jersey only through 1989. Once the federal monies are exhausted, some states may choose to allocate their own funds to support such a program, but others are certain not to do so. For people with incomes too high to qualify for Medicaid or programs like New Jersey's PAAD, this will have serious consequences. AZT was developed through research that was publicly funded. Yet a private company was licensed to produce and sell it for a very high price to people whose ability to afford it is compromised by their mortal illnesses. Such a situation suggests that key policymakers may regard the public health as secondary to private profit.

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